

Giant cell tumours of the bone

If you've recently been diagnosed we have answers

A Sarcoma UK Factsheet produced by the information and support team

This fact sheet explains your diagnosis, your treatment options and what support is available to you.



What is GCT?

Giant cell tumours (GCT) are benign (non cancerous) tumours that develop in the bone. They mostly occur in the long bones found in the arms and legs. GCT often affects people between the ages of 20 and 30 years old.



Signs and symptoms

The most common symptoms of GCT are:

- Pain
- Swelling in the area of the tumour
- Fractures in the bone caused by bone weakness



How is GCT diagnosed?

A specialist doctor will diagnose GCT through a series of tests. These may include:

- Physical examination
- A scan – taking pictures of the inside of the body using x-ray, bone scan, CT or MRI
- A biopsy – taking and testing a tissue sample



Who will treat me?

Although they are benign, GCTs can grow fast and damage the affected bone as well as spread to the soft tissue around it. So it is important that people with a suspected GCT get referred to a specialist sarcoma team for a correct diagnosis and appropriate treatment. These are located in:

- Newcastle
- Manchester & Oswestry
- Birmingham
- Oxford
- London
- Belfast
- Glasgow
- Edinburgh
- Aberdeen

As there are only a small number of centres that treat GCT, you may have to travel some distance for your treatment.



What treatment is available?

The treatment you receive will depend on a number of factors including:

- The size of your tumour
- Where it is in your body
- Your general health and wellbeing

Your doctor or clinical nurse specialist will talk you through your options so you can decide together what the best choice is for you.



Surgery

Usually, the first treatment option for GCT is a type of surgery called curettage. The aim is to clean out the GCT from the bone and then to carefully check that no GCT cells are left behind.

The surgeon will then use a material to try and ensure any remaining GCT cells are killed off. The most common material used is bone cement. It is used to fill the hole left behind when the GCT is removed. This gives immediate support for the bone as it sets very quickly. It also gives off heat when it sets which helps kill off any GCT cells that may have been left behind.

The affected bone can often be quite weakened by the GCT, so structural support is often needed to strengthen the bone by using a bone graft.

Bone grafts involve taking out the affected bone and replacing it with bone from another part of the body or artificial bone. Bone grafts do not have the advantage of killing off tumour cells like cement does. However, if your surgeon is sure that they have cleaned out all the GCT, or if bone cement is not appropriate, then a bone graft may be used.

Sometimes the GCT can destroy a lot of the bone and sometimes the bone is already broken. In this case your surgeon may advise that the safest option is to remove the entire area of affected bone. This will almost always involve the removal of the end of the long bone and will mean that an artificial joint replacement will be needed. This will usually be a specially designed joint replacement like those used for bone sarcoma patients.



What are the advantages and disadvantages of these procedures?

The advantage of a curettage, with or without cement or bone graft, is that you get you keep your own joint. The disadvantage is the risk of the tumour coming back. This can be as high as 50%.

The advantage of surgery to remove the affected bone area is that the whole GCT is removed and there is a very low risk, less than 5%, of it coming back. The disadvantage is that you will probably need an artificial joint replacement. This will never give you normal function and will be at risk of problems in the future such as infection, coming loose and wearing out.

In many situations the surgeon will try curettage. If that does not work then surgery with reconstruction will be used.



Biological therapy

Biological therapies are treatments that affect the way cells work. GCT is sometimes treated with a biological therapy called denosumab.

GCT is caused by giant cells that work like osteoclast cells. These are the cells that break down old bone. GCT cells produce overactive osteoclasts that break down healthy bone cells as well and destroy the bone. Denosumab works by controlling

the activity of GCT cells. It can stop bone damage in people who have GCT of the bone and it can be used to shrink a GCT enough so it can be removed safely through surgery.

Most people will start to find that any pain they have reduces within a few weeks of Denosumab treatment. X-rays and scans will show the GCT shrink a bit, then bone will start to reform at the edges of the cavity within a few months.



What are the side effects of Denosumab?

Denosumab was originally used to treat GCTs in places where they could never be surgically removed or where surgery would be disabling, like the spine, skull or pelvis. Denosumab has proved very effective, but there are increased concerns that it may have long term side effects. These include:

- osteonecrosis of the jaw – damage to the jaw leading to deep ulcers
- pain in the long bones when active
- hypocalcemia – low calcium levels



After treatment

After treatment for GCT, you will have regular follow-up appointments for several years. You should receive a follow-up schedule from your clinical nurse specialist.

- The usual practice will include:
- a chance to discuss symptoms
- looking for any signs of the tumour returning. This may include an x-ray or MRI if required



What if my GCT comes back?

GCT is known to come back in the same area of the original tumour. This is called a local recurrence. If the tumour does reappear, it is important to get treated as quickly as possible. This could involve further surgery or Denosumab treatment.

You can check for recurrences yourself. The most common sign of a GCT recurrence is pain. You may also find a new swelling or a lump. If you are worried about your tumour returning, contact your sarcoma doctor or nurse. They may decide to bring forward your follow up appointment to investigate your concerns.



What if my GCT spreads to another part of my body?

Although it is rare, a recurrence of GCT can be accompanied by GCT cells in other parts of the body. This is called metastasis. This only occurs in about 2-3% of all people affected by GCT. GCT is most likely to spread to the lungs. Treatment for lung metastases can include surgery to remove the tumours or denosumab.

In the very rare case that GCT becomes cancerous and more aggressive it will be treated more like a bone sarcoma. This will involve chemotherapy and more aggressive surgery.

Talking to us



0808 801 0401



supportline@sarcoma.org.uk

Our Support Line offers practical and emotional support and advice to anyone affected by sarcoma.

- Our support line is independent & confidential.
- We believe no question is a silly question.
- We lend a listening ear.

We can point you in the right direction.